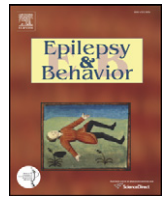


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# Patients' perspectives on antiepileptic medication: Relationships between beliefs about medicines and adherence among patients with epilepsy in UK primary care

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## ABSTRACT

**Background:** Nonadherence to antiepileptic drugs (AEDs) can result in suboptimal outcomes for patients.

**Aim:** This study aimed to assess the utility of a theory-based approach to understanding patient perspectives on AEDs and adherence.

**Method:** Patients with epilepsy, identified by a GP case note review, were mailed validated questionnaires assessing their perceptions of AEDs and their adherence to them.

**Results:** Most (84.9%) of the 398 AED-treated respondents accepted the necessity of AEDs, but over half expressed doubts, with 55% disagreeing or uncertain about the statement 'I would prefer to take epilepsy medication than risk a seizure'. Over a third (36.4%) expressed strong concerns about the potential negative effects of AEDs. We used self-report and medication possession ratio to classify 36.4% of patients as nonadherent. Nonadherence was related to beliefs about medicines and implicit attitudes toward AEDs ( $p < 0.05$ ). Adherence-related attitudes toward AEDs were correlated with general beliefs about pharmaceuticals (BMQ General: General Harm, General Overuse, and General Benefit scales) and perceptions of personal sensitivity to medicines (PSM scale).

**Conclusion:** We identified salient, adherence-related beliefs about AEDs. Patient-centered interventions to support medicine optimization for people with epilepsy should take account of these beliefs.

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## 1. Introduction

The most common treatment modality for people with epilepsy is antiepileptic drugs (AEDs), and these drugs can offer seizure control for over 70% of patients newly diagnosed with epilepsy [1]. However, there is a 'treatment gap' for some people with epilepsy, particularly in low-income countries [2], and suboptimal patient outcomes and reduced quality of life are reported internationally [3,4]. Nonadherence to AEDs can exacerbate the impact of suboptimal care [5] and may result in a 21% increase in the risk of seizures [6]. Between a quarter and two-thirds of patients with epilepsy do not take their medicines as prescribed [4,6]. However, adherence is rarely discussed in consultations, and the problem of nonadherence is often hidden: undisclosed by patients and unrecognized by clinicians [7,8]. Nonadherence is a common but hidden factor in treatment failure. People who are nonadherent to medicines can be identified using a combination of proxy measures [9], but patients and professionals should be assisted to better understand the factors contributing to nonadherence and so improve care for people with epilepsy.

Medicine-taking behavior is dynamic and variable across individual patients, and nonadherence can be intentional or unintentional. Nonadherence may arise from a lack of motivation to take medicines as prescribed due to perceptual barriers such as concerns about adverse effects, doubts about a personal need for medicines, or gaps in knowledge [10–12]. Practical barriers such as difficulty in opening pill caps or difficulties with supply [10,13] can also prevent patients from taking their medicines as prescribed.

The Necessity–Concerns Framework (NCF) postulates that adherence to treatments is the result of the interplay between patients' beliefs in their personal need for treatment (Necessity) and their concerns about the potential adverse consequences of treatment (Concerns) [14]. A recent systematic review of studies assessing the relationship between adherence and treatment beliefs confirmed that the odds of nonadherence were significantly increased when patients reported high concerns and low necessity beliefs [15]. Patients' beliefs about prescribed medicines (e.g., necessity beliefs and concerns) may differ from the views of professionals, derived from evidence of the likely benefits and risks of the treatment. However, they are often based on a common-sense understanding of the illness and treatment [16].

Patients' evaluations of specific medicines prescribed for them may be influenced by more general 'background' beliefs about pharmaceuticals as a class of treatment [14] and by perceptions of personal sensitivity to medicines [16,17]. For example, patients who believe that medicines are

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generally beneficial will perceive higher personal necessity of treatments, whereas those who believe that medications are generally harmful and overused and that they are personally sensitive to the effects of treatments will have more concerns about specific treatments [18,19].

Annual reviews have been recommended as a method to improve epilepsy care [20] and offer the patient and their healthcare professionals an opportunity to discuss the individual's beliefs about medicines. Interventions to improve adherence to AEDs have had mixed success [21]. However, the annual review provides an opportunity to improve clinical outcomes through improving adherence.

The current study, therefore, investigated and quantified patients' beliefs about medicines within a UK community sample of patients with epilepsy, and the role of beliefs in nonadherence to AEDs. Previous studies have established a role for beliefs about medicines in nonadherence in US specialty epilepsy clinics [10,11,22]; however, it is not clear whether these findings would extend to community samples or outside the US. We hypothesized that patients who have concerns about the potential adverse consequences of AEDs and doubts about the personal necessity of AEDs would be more nonadherent and that these specific beliefs about AEDs would be correlated with general background beliefs about medicines as a class of treatment. We also explored whether demographic and clinical factors were associated with these beliefs.

## 2. Materials and methods

This study received ethical approval from the North Eastern MREC and research governance approval from the North Yorkshire Research Alliance and the West Hull PCT and Eastern Hull PCT.

All participants provided consent by accepting the invitation to participate and completing the postal questionnaire.

### 2.1. Participants

Adult patients with epilepsy were identified from 27 GP practices in 3 primary care trusts (Selby/York PCT, West Hull PCT, and Eastern Hull PCT) through a case note review conducted by DH and WHS [23]. Patients who were incorrectly coded as having epilepsy or who were misdiagnosed were excluded to ensure that the target population included all adults (aged 18 or older) with epilepsy at the identified practices. Patients were excluded if they had a learning disability or memory impairment and if their GP thought that they would not be able to complete the questionnaire or that they would be distressed by the questionnaire. Patients were also excluded if they had left the practice or died by the time questionnaires were distributed. From a total practice population of 161,500, 1333 adults with epilepsy were identified, 832 questionnaires were sent out, and 461 (55%) were returned, of which 438 were completed responses. Of these, 398 (91%) patients who reported that they were currently taking AEDs were selected for analysis within the current study.

### 2.2. Measures

#### 2.2.1. Demographics

Patients were asked to provide their age in years, gender, employment status (employed, retired, homemaker, in education, unemployed, or other), marital status (married/cohabiting, single, divorced, widowed, living with parents or relatives, or living alone), and highest level of educational qualification obtained (school-leaving qualification aged 16 years, advanced-level school-leaving qualifications, diploma/degree, or no formal qualification).

#### 2.2.2. Seizure and epilepsy history

Patients were asked how many seizures they had had in the past year, how long it had been since their last seizure, whether they tended to have seizures when awake or asleep, if they had a family history of epilepsy, and how old they were when they were diagnosed with epilepsy.

#### 2.2.3. Beliefs about Medicine Questionnaire (BMQ)

The BMQ [14,24] (copyright R. Horne) comprises two sections. The BMQ-Specific assesses beliefs about specific medicines prescribed for a particular condition (e.g., asthma, depression, and epilepsy), and the BMQ-General assesses more general beliefs about pharmaceuticals as a class of treatment [14].

**2.2.3.1. BMQ-Epilepsy Specific.** The BMQ-Specific [14] was adapted for an epilepsy population as recommended in the literature [22]. It comprised two scales: a 6-item AED-Necessity scale, assessing patients' perceptions of their personal need for AEDs and a 10-item AED-Concerns scale, assessing concerns about the potential negative effects of taking AEDs. The five core items of the BMQ-Specific Necessity scale [14] were augmented by an additional epilepsy-specific item 'I would prefer to take my epilepsy medicine rather than risk having a seizure'. The five core items of the BMQ-Specific Concerns scale were augmented by five more epilepsy-specific items: 'My epilepsy medicine causes unpleasant side effects', 'Taking my epilepsy medicines makes me feel labeled as an 'ill person'', 'I have received enough information about my epilepsy medicines' (reverse scored), 'I sometimes worry that my antiepileptic medicine slows me down', and 'I sometimes worry that my epilepsy medicines affect my relationship with others'.

The resulting BMQ-Epilepsy Specific scales were reviewed by a study panel comprising epilepsy patients, clinicians, and the study team. Post hoc Cronbach's  $\alpha$  demonstrated that the internal reliability of the BMQ-Epilepsy Specific scales was acceptable (AED-Necessity  $\alpha = 0.836$ ; AED-Concerns  $\alpha = 0.839$ ).

All BMQ-Epilepsy Specific items were scored on a five-point Likert-type scale (where 1 = strongly disagree, 2 = disagree, 3 = uncertain, 4 = agree, and 5 = strongly agree). By summing scores on the individual items, AED-Necessity and AED-Concerns scale scores were computed. A mean item score (range: 1–5) was then computed by dividing the scale score by the number of items in the scale. Higher scores indicate higher agreement with the construct represented by the scale.

A Necessity-Concerns Differential (NCD) was calculated by subtracting AED-Concerns scores from AED-Necessity scores. The NCD score provides a numerical indicator of how the individual judges their personal need for AEDs relative to their concerns about the potential negative effects of taking AEDs. It provides a one-dimensional indicative representation of the outcome of a 'cost-benefit evaluation' where the assessment is likely to be implicit, rather than a purely 'rational' assessment of benefits and costs [19,25]. The NCD scores range from  $-4$  to  $+4$ , with positive scores indicating higher ratings of AED-Necessity relative to AED-Concerns.

Finally, we divided patients into 4 attitudinal groups by dichotomizing participants based on whether they scored over the AED-Necessity and AED-Concerns scale midpoint of 3. Participants were then grouped into patients who were Accepting (High Necessity and Low Concerns), Indifferent (Low Necessity or Low Concerns), Skeptical (Low Necessity or High Concerns), or Ambivalent (High Necessity or High Concerns) about AEDs [16,26].

**2.2.3.2. BMQ-General.** The BMQ-General questionnaire has three subscales. (1) General Harm (5 items) assesses perceptions of the intrinsic properties of medicines and the degree to which they are perceived as fundamentally harmful, addictive poisons, e.g., 'Medicines do more harm than good' and 'All medicines are poisons'. Although in the original BMQ validation paper [24] this was a 4-item scale, one item ('Natural remedies are safer than medicines') loaded onto both General Overuse and General Harm factors, with only a slightly greater loading on General Overuse. In some subsequent studies, including in the current sample, this item loaded more strongly onto the General Harm scale and so is included in the General Harm scale below. (2) General Overuse (3 items) assesses perceptions of how medicines are prescribed and the degree to which they are perceived as being overused by clinicians, e.g., 'Doctors place too much trust in medicines'

and 'If doctors had more time they would prescribe fewer medicines'. (3) General Benefit (4 items) assesses perceptions of the general benefits of pharmaceuticals, e.g., 'In most cases the benefits of medicines outweigh the risks' and 'Medicines help many people to live better lives'.

All BMQ-General items were scored on a five-point Likert-type scale (where 1 = strongly disagree and 5 = strongly agree). Scale scores were computed by summing scores on the individual items. A mean item score (range: 1–5) was then computed by dividing the scale score by the number of items in the scale. Higher scores indicate higher agreement with the construct represented by the scale. Within the current sample, the scales had acceptable internal reliability (General Overuse Cronbach's  $\alpha = 0.741$ , General Harm Cronbach's  $\alpha = 0.579$ , and General Benefit Cronbach's  $\alpha = 0.538$ ).

#### 2.2.4. Perceived Sensitivity to Medicines (PSM) scale

The PSM [17] comprises 5 items assessing perceptions of personal susceptibility to the effects of medicines, e.g., 'My body overreacts to medicines' and 'I usually have stronger reactions to medicines than most people'. Perceived sensitivity to medicines items were scored on a five-point Likert-type scale (where 1 = strongly disagree and 5 = strongly agree). Scale totals were computed by summing scores on the individual items. A mean item score (range: 1–5) was then computed by dividing the scale score by the number of items in the scale. Higher scores indicate higher agreement with the construct represented by the scale. The PSM scale had acceptable internal reliability within the study sample (Cronbach's  $\alpha = 0.842$ ).

#### 2.2.5. Adherence assessment

Patients were grouped into adherent vs. nonadherent categories using a combination of self-report and medication possession ratio.

**2.2.5.1. Self-reported medication-taking behavior.** This was assessed by using 2 items from the Epilepsy Self-Management Scale (ESMS) [5]: 'I skip doses of my seizure medication because I do not remember to take it' and 'I skip doses of my seizure medication'. Items were scored 1–5 based on whether participants reported 'never', 'rarely', 'sometimes', 'most of the time', or 'always' being nonadherent. These scores were summed resulting in a score range of 0–10, with higher scores indicating greater adherence.

**2.2.5.2. Medication possession ratio (MPR).** This provided a further indicator of medication-taking behavior. Medication possession ratio was calculated using patients' medication records [27].

**2.2.5.3. Combining self-report and MPR.** Where MPR was calculated as  $<0.8$  or the self-reported adherence score was less than 8 out of 10, patients were classed as 'nonadherent', and where patients scored 9 or 10 on the self-report measure and MPR was calculated as  $>0.8$ , patients were classed as adherent. For 18 (4.6%) patients, it was not possible to calculate MPR data from medication records, and so they were classified on the basis of their self-reported adherence scores alone.

### 2.3. Analysis

Associations between adherence and demographic, clinical, and attitudinal predictors were tested using independent t-tests (relationship of attitudes with high/low adherence, educational qualifications, gender, and seizure history), correlations (relationships between attitudes and relationship between age and attitudes),  $\chi^2$  tests (relationship between attitudinal groups and high/low adherence), and logistic regression (prediction of low adherence using attitudinal variables). Two-tailed tests and  $\alpha = 0.05$  were used to assess the statistical significance of the results. Analyses were conducted using IBM SPSS Statistics v21. Where fewer than half of item scores were missing from a participant's response on the BMQ or PSM, scores were prorated.

## 3. Results

### 3.1. Patient demographics and seizure frequency

Just over half (54.6%) of the respondents were female. The mean age of the patients sampled was 49.9 years. Most (60.8%) were married/cohabiting, 40.4% were employed, and 43.0% had no educational qualifications (see Table 1). Over half (59.1%) of the sample had not had a seizure in the past year, and 36.9% had had a seizure in the previous year. The mean age when diagnosed with epilepsy was 25.12 years (sd = 16.26).

### 3.2. Perceptions of medication

#### 3.2.1. Perceptions of AEDs

We dichotomized the AED-Necessity and AED-Concerns scales at their midpoint. Most patients were convinced of their personal need for AEDs; however, 15.1% of the patients expressed strong doubts about the necessity of AEDs (scores  $>$  midpoint on the AED-Necessity scale). Over a third (36.4%) expressed strong concerns about the potential negative effect of taking AEDs (scores  $>$  midpoint on the AED-Concerns scale).

A more comprehensive insight into patients' views about their AEDs is provided by an analysis of responses to the individual items on the AED-Necessity and AED-Concerns scales (Figs. 1 and 2, respectively). Although most patients broadly endorsed statements about their personal need for AEDs (scores  $>$  midpoint on the AED-Necessity scale), many expressed doubts about the necessity for AEDs. For example, 55.5% doubted that 'Without my epilepsy medicines I would be very ill', and 53.0% were uncertain or disagreed with the statement 'I would prefer

**Table 1**  
Participant clinical and demographic information.

|  | m (sd)        |
|--|---------------|
| Age (years) <sup>d</sup>                         | 49.92 (16.44) |
|  | n (%)         |
| Female <sup>a</sup>                              | 215 (54.6%)   |
| Employment <sup>b</sup>                          |               |
| Employed   | 159 (40.4%)   |
| Retired  | 111 (28.2%)   |
| Houseworker                                      | 40 (10.2%)    |
| In education                                     | 7 (1.8%)      |
| Unemployed                                       | 34 (8.6%)     |
| Marital status <sup>c</sup>                      |               |
| Married/cohabiting                               | 240 (60.8%)   |
| Single   | 70 (17.7%)    |
| Divorced   | 37 (9.4%)     |
| Widowed  | 21 (5.3%)     |
| Highest educational qualification <sup>d</sup>   |               |
| Diploma/degree                                   | 79 (20.7%)    |
| AS/A levels                                      | 23 (6.0%)     |
| CSE/GCSE/O levels                                | 108 (28.3%)   |
| Other (NVQ)                                      | 1 (0.3%)      |
| No qualifications                                | 171 (43.0%)   |
| Number of seizures in the past year <sup>e</sup> |               |
| None   | 222 (56.5%)   |
| 1–10   | 90 (22.9%)    |
| $>10$  | 81 (20.6%)    |
| Time since last seizure <sup>f</sup>             |               |
| $<1$ year  | 156 (44.7%)   |
| 1–5 years  | 98 (28.1%)    |
| $>5$ years                                       | 95 (27.2%)    |

<sup>a</sup> 16 patients missing.

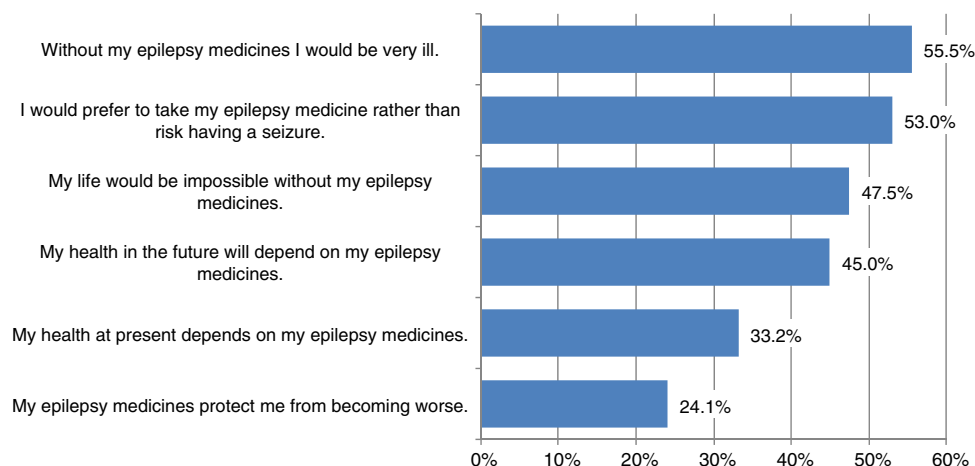
<sup>b</sup> 4 patients missing.

<sup>c</sup> 3 patients missing.

<sup>d</sup> 16 patients missing.

<sup>e</sup> 5 patients missing.

<sup>f</sup> 49 patients missing.



**Fig. 1.** Percentages of patients expressing doubts about their need for AEDs, as indicated by responding 'uncertain', 'disagree', or 'strongly disagree' on AED-Necessity items.

to take my epilepsy medicine rather than risk having a seizure'. Likewise, individual concerns were prevalent, with 47.8% patients concerned about the long-term effects of AEDs and 42.2% reporting concern that AEDs 'slow me down'.

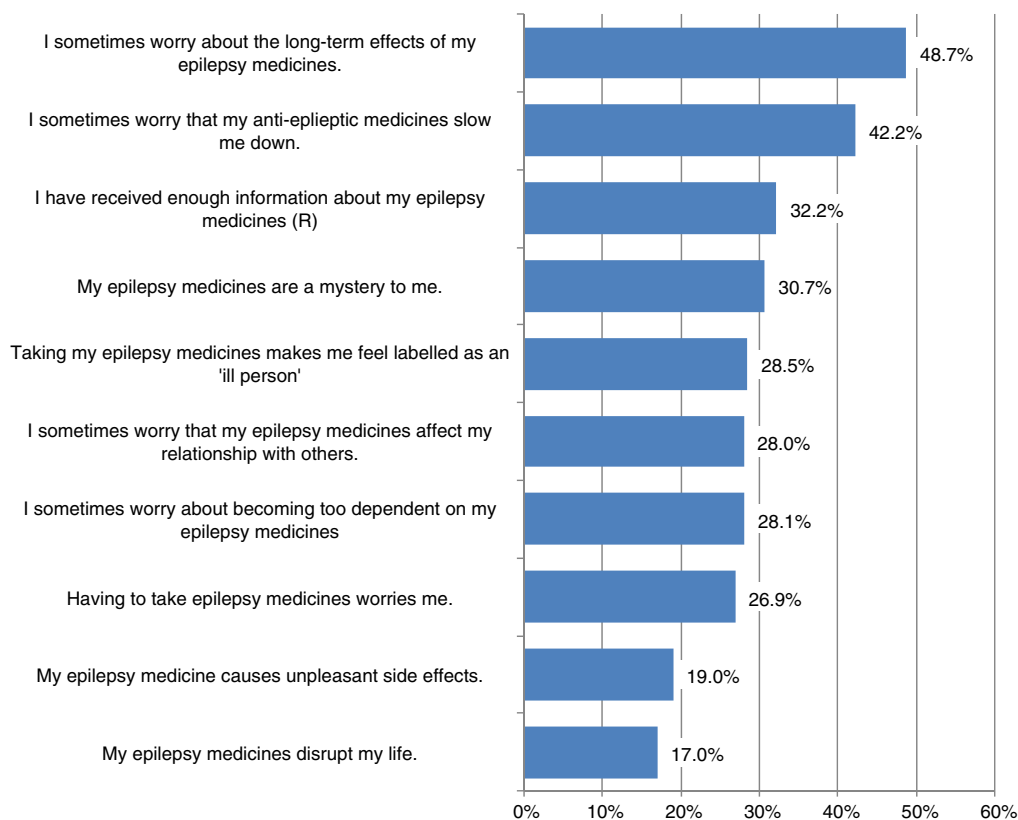
### 3.2.2. Attitudinal analysis of perceptions of AEDs

Participants were categorized into attitudinal groups based on whether they scored above or below the scale midpoint for the AED-Necessity and AED-Concerns scales [26]. Just over half of respondents were completely Accepting of AEDs as defined by higher-than-midpoint scores on the AED-Necessity scale and lower-than-midpoint scores

on the AED-Concerns scale. Approximately a third were Ambivalent, having high necessity beliefs and high concerns. The remainder were Skeptical, having low necessity beliefs and high concerns, or Indifferent, having low necessity and low concerns (see Fig. 3).

### 3.2.3. General beliefs about pharmaceuticals as a class of treatments

Participants were categorized into groups holding high or low beliefs about pharmaceuticals as a class of treatment based on the scale midpoint. Most patients believed that medicines were generally beneficial, with 95.5% ( $n = 380$ ) scoring above the scale midpoint. Only 20.9% ( $n = 83$ ) indicated a high belief that medicines were



**Fig. 2.** Percentages of patients expressing concerns about AEDs, as indicated by responding 'agree' or 'strongly agree' to AED-Concerns items.



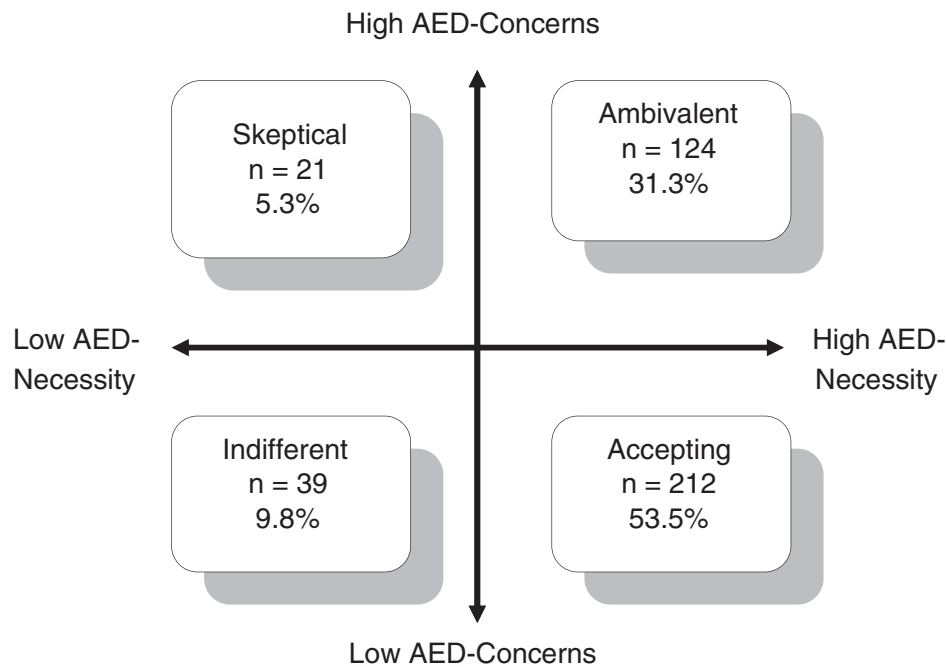


Fig. 3. Attitudinal analysis of patients' beliefs about AEDs.

generally harmful. However, 58.9% ( $n = 234$ ) had a high belief that medicines are generally overused (see Fig. 4).

### 3.3. Perceived sensitivity to medicines

Just under a third of participants viewed themselves as highly sensitive to the effects of medicines, (30.8%,  $n = 122$ ), scoring above the scale midpoint.

### 3.4. Relationship between specific beliefs about AEDs and general background beliefs about medicines

As predicted by our theoretical model [18], AED-Necessity beliefs were significantly positively correlated with General Benefit beliefs. General Harm, General Overuse, and PSM were significantly positively correlated with AED-Concerns. The NCD was negatively associated with General Harm, General Overuse, and PSM and positively associated with General Benefit (all  $p < 0.001$ ) (see Fig. 5 for correlations).

### 3.5. Adherence to AEDs

Approximately one-third of the patients were placed in the low adherence category based on their combined MPR rating and self-report responses,  $n = 146$  (36.7%), with the remainder allocated to the high adherence category,  $n = 252$  (63.3%).

### 3.6. Adherence and specific beliefs about AEDs, general beliefs about medicines, and perceived sensitivity to medicines

Analysis of the Specific belief scales indicated that nonadherent patients had a stronger belief in their personal need for AEDs and more concerns about their potential adverse effects ( $p < .05$ ). The NCD score was significantly lower in the nonadherent patients, indicating that their beliefs in their personal need for AEDs were more closely matched to concerns about their treatment (see Fig. 6).

Nonadherent patients also believed that medicines were generally more overused and harmful, as indicated by General Harm and General Overuse scores. However, the groups did not differ significantly on the General Benefit and PSM scales (see Table 2).

Logistic regression analysis indicated that the odds of nonadherence were significantly increased when patients' concerns about AEDs increased and significantly reduced when beliefs in their personal need for AEDs, the NCD, and beliefs in the harm and overuse of medicines, in general increased (Table 3). The General Benefit and PSM scores did not significantly predict nonadherence.

### 3.7. Attitudinal analysis of beliefs about AEDs for regular use and nonadherence

Nonadherence rates varied significantly across attitudinal groups,  $\chi^2(3, n = 396) = 14.93, p = 0.002$ . More than half (61.9%) of the Skeptical participants were nonadherent, a lower proportion of Ambivalent and Indifferent participants were nonadherent (44.4% of Ambivalent participants; 41.0% of Indifferent participants), and only 28.8% of Accepting participants were nonadherent (see Fig. 7).

### 3.8. Seizure history and beliefs about medicines

Patients who did not report a seizure in the past year had more negative specific beliefs about medicines compared with patients who reported one or more seizures within the past year. These patients also had higher scores on the General Harm and PSM scales (see Table 4).

Post hoc tests indicated that AED-Necessity was higher in patients who had a seizure within the past year than in patients who had had a seizure more than 5 years ago. In patients who had had a seizure in the past year than other patients, AED-Concerns, General Harm beliefs, and PSM were higher. No other contrasts were significant at the 0.05 level.

### 3.9. Demographic factors and beliefs about medicines

Personal sensitivity to medicines scores were higher in female ( $m = 2.60, s = 0.79$ ) than in male patients ( $m = 2.38, s = 0.76, t(390) = 2.68, p < 0.01$ ). No other significant gender differences in beliefs were found.

There was a negative correlation between patient age and AED-Concerns indicating that younger patients tended to have greater concerns,  $r(380) = -0.184, p < 0.001$  and a lower NCD score,  $r(380) = 0.204, p < 0.001$ . General Benefits scores were higher in older

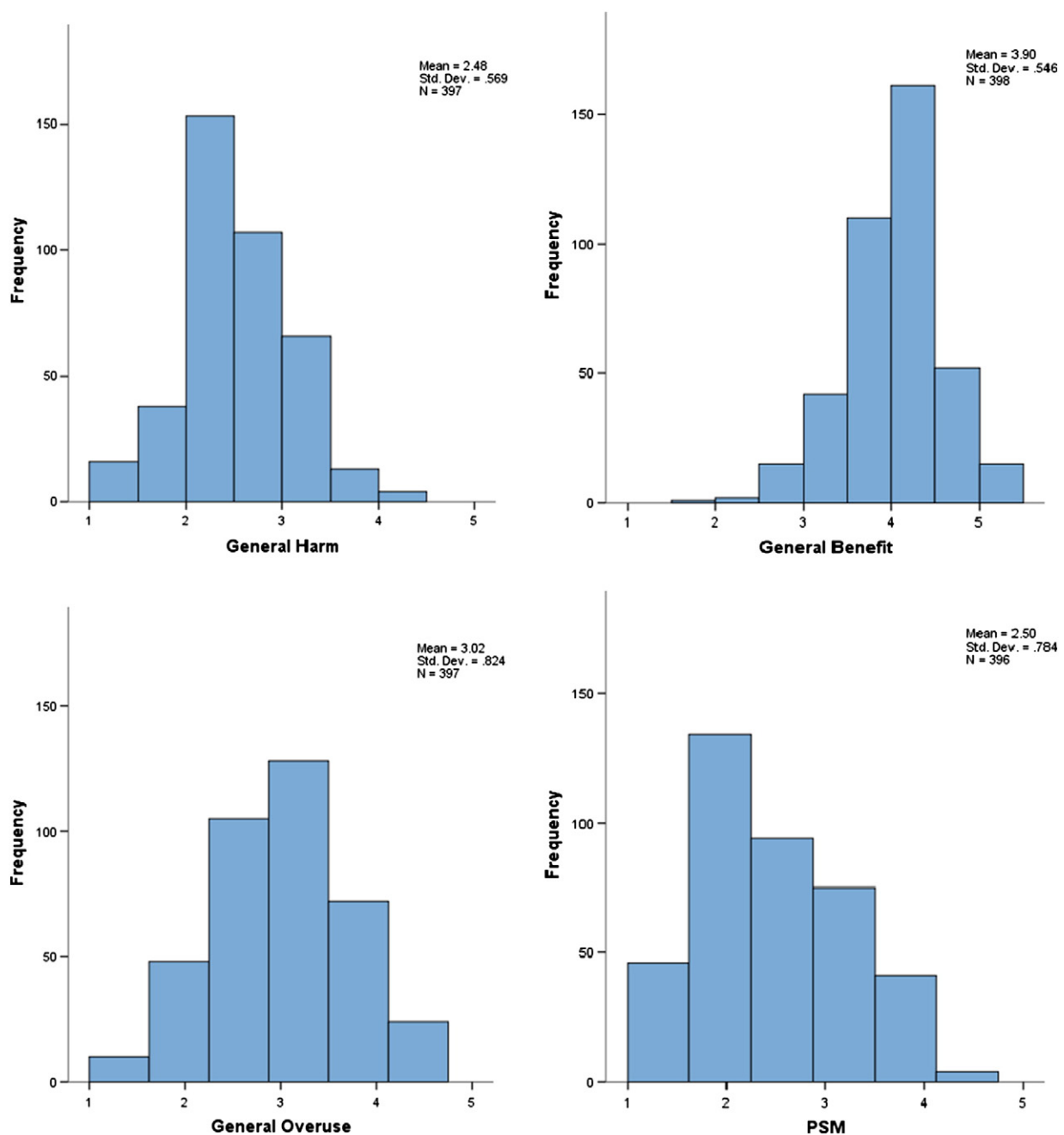


Fig. 4. Frequency distributions for general background beliefs about medicines in this sample of patients with epilepsy.

patients,  $r(382) = 0.128$ ,  $p < 0.05$ . No other significant associations between beliefs and age were found.

Relative to patients with no educational qualifications, patients with qualifications including CSE/GCSE/O levels, AS or A levels, or diplomas or degrees had lower AED-Necessity scores and lower NCD scores, indicating more negative beliefs about their specific medicine (see Table 5).

#### 4. Discussion

To our knowledge, this study is the first to assess the treatment beliefs of a UK community sample of patients with epilepsy and to evaluate the role of medication perceptions in adherence to AEDs in this group. We found that most patients were convinced of the necessity of AEDs, but 15% doubted their personal need for AEDs. Almost a third of patients reported strong concerns about the potential negative effects of AEDs. Beliefs about AEDs were related

to nonadherence. Nonadherent patients were significantly more likely to have negative perceptions of their AED medication, with stronger doubts about their personal need for AEDs and stronger concerns about potential harm.

A further insight into patients' implicit evaluations of AEDs was provided by an attitudinal analysis combining AED-Necessity and Concern ratings. Attitudinal analysis showed that most patients were Accepting of their AEDs (high AED-Necessity with low AED-Concerns). Skeptical patients who had high doubts about their need for AEDs and concerns about the potential adverse effects were more likely to be nonadherent.

These results indicate that patients with epilepsy may not adhere to their AEDs, in part, because of negative beliefs about their medicines, confirming the applicability of the Necessity–Concerns Framework [28] to this UK community sample. These findings are consistent with previous findings in US specialist care [10,11,22] and with results in patients with a range of long-term conditions [15].



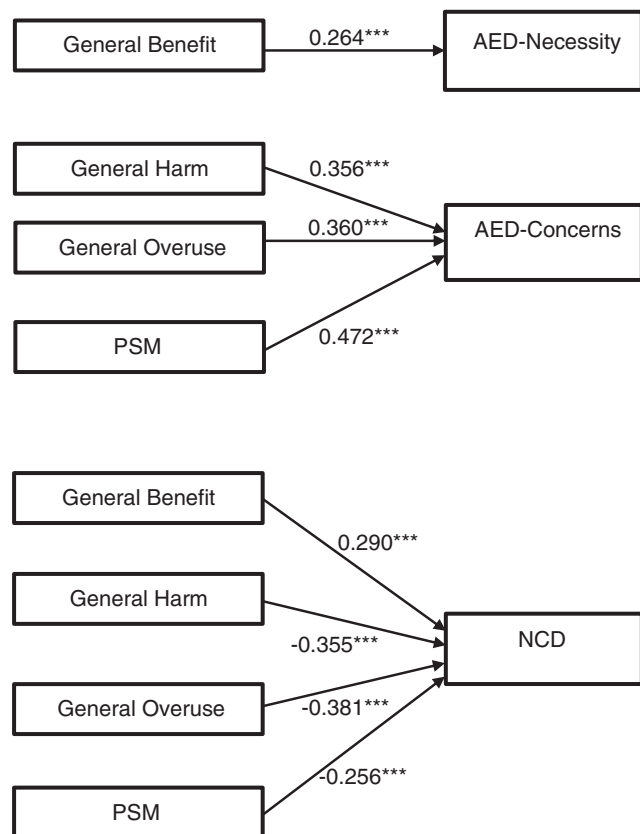


Fig. 5. Correlations between specific beliefs about AEDs and general background beliefs. \*\*\*  $p < 0.001$ .

Within the Necessity–Concerns Framework, adherence to medications is influenced by patients' evaluation of their personal need for AEDs against their concerns about the potential adverse consequences

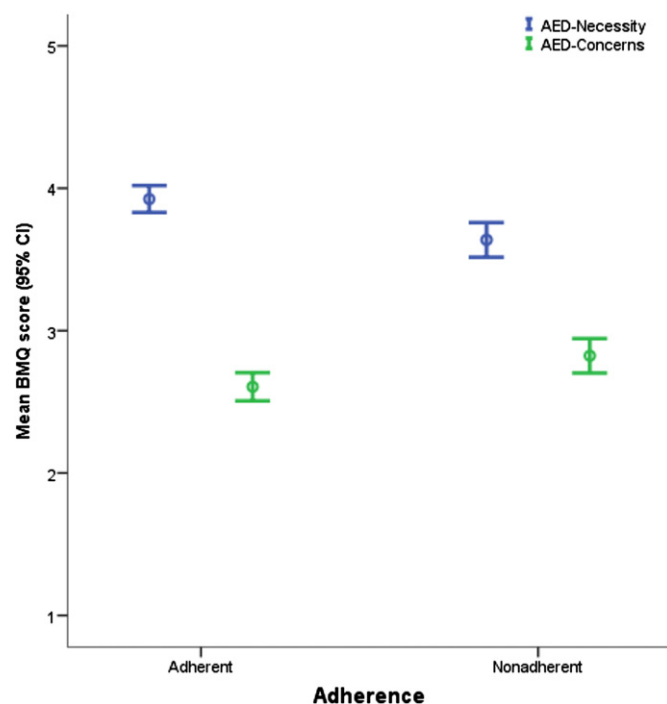


Fig. 6. AED-Necessity and AED-Concerns scores in adherent and nonadherent patients.

Table 2

Adherent and nonadherent patients' beliefs about medicines.

|                              | Nonadherent<br>n = 143<br>m (sd) | Adherent<br>n = 252<br>m (sd) |                                    |
|------------------------------|----------------------------------|-------------------------------|------------------------------------|
| AED-Necessity <sup>a</sup>   | 3.64 (0.75)                      | 3.92 (0.78)                   | <b>t(392) = 3.63, p &lt; 0.001</b> |
| AED-Concerns <sup>a</sup>    | 2.82 (0.74)                      | 2.61 (0.80)                   | <b>t(392) = 2.69, p &lt; 0.01</b>  |
| NCD <sup>a</sup>             | 0.82 (0.98)                      | 1.32 (1.07)                   | <b>t(392) = 4.59, p &lt; 0.001</b> |
| General Harm <sup>a</sup>    | 2.58 (0.57)                      | 2.43 (0.57)                   | <b>t(392) = 2.61, p &lt; 0.05</b>  |
| General Overuse <sup>a</sup> | 3.17 (0.81)                      | 2.93 (0.82)                   | <b>t(392) = 2.82, p = 0.050</b>    |
| General Benefit              | 3.89 (0.52)                      | 3.92 (0.55)                   | t(393) = 0.44, p > 0.05            |
| PSM <sup>b</sup>             | 2.56 (0.77)                      | 2.47 (0.80)                   | t(391) = 1.08, p > 0.05            |

Bold values indicate significant differences at the 0.05 level.

<sup>a</sup> 1 patient missing.

<sup>b</sup> 2 patients missing.

of the medication. Moreover, theories of medication representation [19,29] suggest that patients' implicit evaluations of specific medication prescribed for them are influenced by more general background beliefs about medicines, including social representations of pharmaceuticals as a class of treatments and perceptions of personal sensitivity to medicines. Our findings support this model in that patients with more negative perceptions about pharmaceuticals as a class of treatment and those who perceived themselves to be more sensitive to the effects of medicines had significantly stronger concerns about their AEDs and were, in turn, significantly more likely to be nonadherent.

Beliefs about medicines were associated with clinical and demographic factors within the sample, such that patients had two or more seizures in the past year reported more concerns about their epilepsy medicines and were more likely to believe that they were generally sensitive to the effects of medicines and that medicines are generally harmful. However, they also believed that they had a greater need of their epilepsy medicines. Female patients with epilepsy perceived their personal sensitivity to medicines to be higher than male patients. Younger patients were more concerned about the potential adverse consequences of medicine, and patients with any educational qualifications (school-leaver, vocational, degree and postgraduate qualifications) had more doubts about their personal need for medicines (AED-Necessity) compared with patients without any formal qualifications.

This study has several limitations. Firstly, it was an observational, cross-sectional study, and, therefore, cannot assess whether treatment beliefs cause nonadherence. Moreover, it is possible that the relationships described above may not be generalizable to those patients who did not respond to the survey and to populations in other healthcare settings (e.g., secondary care) or to other locations (e.g., outside the UK). Medication beliefs may vary across different cultural groups [30]; however, we did not investigate cultural factors within the present study. Prospective longitudinal designs in a wide range of settings are needed to fully assess whether beliefs can be used to predict later nonadherence. We also did not use a validated measure of adherence assessment. Although the Epilepsy Self-Management Scale has been validated as a measure of general self-management behavior in epilepsy [5], the individual items were not recommended for use in this way.

Table 3

Logistic regression analysis of the odds of nonadherence predicted by beliefs.

|                 | OR [95% CI]                 | p                |
|-----------------|-----------------------------|------------------|
| AED-Necessity   | <b>0.608 [0.460, 0.802]</b> | <b>&lt;0.001</b> |
| AED-Concerns    | <b>1.419 [1.087, 1.854]</b> | <b>&lt;0.01</b>  |
| NCD             | <b>0.624 [0.504, 0.771]</b> | <b>&lt;0.001</b> |
| General Harm    | <b>1.622 [1.121, 2.346]</b> | <b>&lt;0.01</b>  |
| General Overuse | <b>1.434 [1.111, 1.850]</b> | <b>&lt;0.01</b>  |
| General Benefit | 0.920 [0.632, 1.339]        | >0.05            |
| PSM             | 1.155 [0.889, 1.500]        | >0.05            |

Bold differences indicate significant predictors of nonadherence at the 0.05 level.

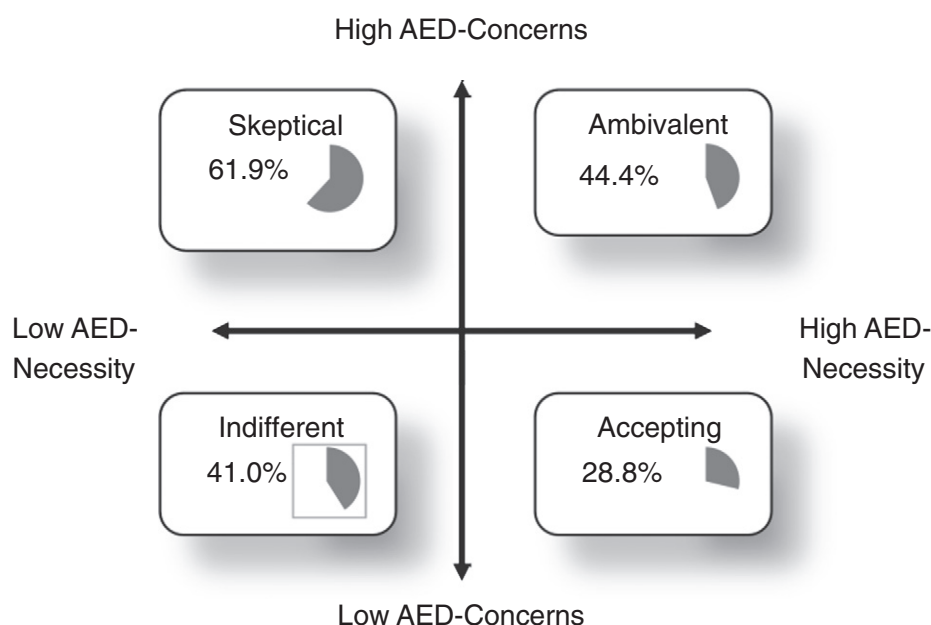


Fig. 7. Rates of nonadherence among participants in each attitudinal group based on AED-Necessity and AED-Concerns scores.

However, the validity of using this approach within the current sample has been explored within a previous paper [9]. Finally, the internal consistency of two of the BMQ General subscales was poor within the current sample, which may have meant that we underestimated the magnitude of the relationships between general beliefs and specific beliefs and adherence found within the current study. The small number of items used within these scales and the use of single items to assess disparate topics may have contributed to the low internal consistency.

## 5. Conclusions

Despite its limitations, this study was the first to quantify patients' perceptions of AED medication in UK primary care and to link perceptions to adherence. The findings indicate that patients' personal evaluations of

AEDs may differ from the medical view yet appear to influence adherence. Patients' implicit evaluations of their personal need for AEDs relative to their concerns about the potential adverse consequences of taking AEDs appear to be particularly salient.

Our findings support the utility of patients' beliefs about medicines as an indicator of their likely adherence to AEDs. In addition, our results suggest that groups of individuals who are less adherent, for example, younger patients with epilepsy [31], may also have greater concerns about AEDs and more doubts about their personal need for AEDs. Unlike the demographic and clinical factors also associated with adherence within this sample [9], beliefs are more readily modifiable.

Within a clinical setting, the Necessity–Concerns Framework informed that interventions which address maladaptive beliefs about AEDs may, therefore, hold the potential to increase adherence, partly reducing inequalities in healthcare and improving the quality of life

**Table 4**  
Seizure history and beliefs about medicines.

| Number of seizures in the past year | None<br>n = 222<br>m (sd)    | ≥ 1 seizure<br>n = 171<br>m (sd) |                                    |                                       |
|-------------------------------------|------------------------------|----------------------------------|------------------------------------|---------------------------------------|
| AED-Necessity                       | 3.70 (0.73)                  | 3.99 (0.78)                      | <b>t(390) = 3.78, p &lt; 0.001</b> |                                       |
| AED-Concerns                        | 2.51 (0.74)                  | 2.93 (0.78)                      | <b>t(389) = 5.48, p &lt; 0.001</b> |                                       |
| NCD                                 | 1.19 (1.00)                  | 1.05 (1.13)                      | t(389) = 1.27, p > 0.05            |                                       |
| General Harm                        | 2.40 (0.52)                  | 2.58 (0.62)                      | <b>t(390) = 3.16, p &lt; 0.01</b>  |                                       |
| General Overuse                     | 2.97 (0.78)                  | 3.08 (0.88)                      | t(390) = 1.32, p > 0.05            |                                       |
| General Benefit                     | 3.93 (0.56)                  | 3.87 (0.53)                      | t(391) = 1.06, p > 0.05            |                                       |
| PSM                                 | 2.36 (0.76)                  | 2.68 (0.77)                      | <b>t(389) = 4.16, p &lt; 0.001</b> |                                       |
| Time since last seizure             | <1 year<br>n = 155<br>m (sd) | 1–5 years<br>n = 98<br>m (sd)    | >5 years<br>n = 95<br>m (sd)       |                                       |
| AED-Necessity                       | 4.00 (0.78)                  | 3.77 (0.74)                      | 3.54 (0.70)                        | <b>F(2,345) = 11.21, p &lt; 0.001</b> |
| AED-Concerns                        | 2.94 (0.78)                  | 2.51 (0.69)                      | 2.51 (0.80)                        | <b>F(2,344) = 13.57, p &lt; 0.001</b> |
| NCD                                 | 1.06 (1.12)                  | 1.26 (0.99)                      | 1.03 (0.11)                        | F(2,344) = 1.42, p > 0.05             |
| General Harm                        | 2.58 (0.62)                  | 2.39 (0.52)                      | 2.37 (0.54)                        | <b>F(2,345) = 5.40, p &lt; 0.01</b>   |
| General Overuse                     | 3.10 (0.88)                  | 2.94 (0.79)                      | 3.03 (0.80)                        | F(2,345) = 1.13, p > 0.05             |
| General Benefit                     | 3.87 (0.55)                  | 3.97 (0.57)                      | 3.92 (0.52)                        | F(2,346) = 1.12, p > 0.05             |
| PSM                                 | 2.68 (0.77)                  | 2.32 (0.79)                      | 2.38 (0.75)                        | <b>F(2,344) = 8.35, p &lt; 0.001</b>  |

Bold values indicate significant differences between groups at the 0.05 level.

**Table 5**  
Educational qualifications and beliefs about medicines.

| Formal educational qualifications | None<br>n = 171<br>m (sd) | Any<br>n = 211<br>m (sd) |                                   |
|-----------------------------------|---------------------------|--------------------------|-----------------------------------|
| AED-Necessity                     | 3.90 (0.77)               | 3.74 (0.75)              | <b>t(379) = 2.01, p &lt; 0.05</b> |
| AED-Concerns                      | 2.60 (0.75)               | 2.75 (0.81)              | t(378) = 1.89, p > 0.05           |
| NCD                               | 1.30 (1.07)               | 0.99 (1.06)              | <b>t(378) = 2.76, p &lt; 0.01</b> |
| General Harm                      | 2.54 (0.51)               | 2.43 (0.60)              | t(379) = 1.75, p > 0.05           |
| General Overuse                   | 2.96 (0.74)               | 3.08 (0.89)              | t(379) = 1.39, p > 0.05           |
| General Benefit                   | 3.92 (0.57)               | 3.89 (0.52)              | t(380) = 0.46, p > 0.05           |
| PSM                               | 2.44 (0.77)               | 2.55 (0.81)              | t(378) = 1.37, p > 0.05           |

Bold values indicate significant differences between groups at the 0.05 level.

of patients. Using a valid and reliable questionnaire, AED-Necessity beliefs and Concerns can be easily quantified, enabling the assessment of patients' beliefs about their AEDs as part of adherence support. Personalized interventions targeted to address individual patients' doubts about AED necessity and concerns about potential adverse effects could then be implemented. The systematic development of adherence support targeted to address specific perceptual factors (e.g., necessity beliefs and concerns) as well as practical barriers (such as capacity and resources influencing the capability to adhere) is a priority for research and practice.

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